LOVE
WITHOUT
WALLS
Dedicated to caregivers.
Acknowledgements

Creative Hub would like to express our sincere gratitude to the National Arts Council and Innerbalance Pte Ltd who gave us the support and funding to embark on this meaningful project, “Love Without Walls”. Secondly, we would also like to acknowledge and thank the facilitators Stephanie Kwok and Sharmini Winslow who provided their time and effort to the caregivers who attended the sessions. Last but not least, to the participants of “Love Without Walls”, your presence and participation paved the way for heart-warming sessions of sharing and fun. Thank you for making time.
Preface

When someone develops schizophrenia, a frightening illness that often lasts a lifetime, many walls come up in their lives. There is a wall of negative experiences that overwhelm sufferers, causing them to respond either by hurting themselves, hurting those they love or withdrawing into their hidden catatonic world. Incomprehensible experiences of sounds and sights that do not exist, of beliefs and fears that are not true reduce the sufferer to a life of increasing isolation and abandonment.

There is a wall of silence as family and friends are afraid of interacting with them, and society with its stigma, choosing to ignore rather than confront their needs. In the past, such sufferers were left in large asylums. Today, there is better understanding of the illness but much work still needs to be done.

Finally, there is a wall of missed opportunities as many sufferers are struck down in the prime of their lives. People with mental illness tend to fall into lower socioeconomic groups and eventually become vagrant. Physical health issues become a source of problems and worldwide studies have shown that they will die some 20 years before their contemporaries. It is in the light of this that the search to find meaning and hope is critical. Medication may ameliorate symptoms but will never help bring down the walls. This needs the help of family and caregivers who must be equipped with tools to knock down these walls.

This project by the Singapore Association for Mental Health, aptly named “Love Without Walls” is sponsored by the National Arts Council and Innerbalance Pte Ltd. It is targeted mainly at all caregivers of people with mental illness. Through song writing, dance, movement, art making and experiential art, caregivers document their experiences to find support and hope. It was our pleasure conducting this project and we trust you will enjoy the results of their loving and lovely contributions.

A/Prof Daniel Fung
President, Singapore Association for Mental Health
The Singapore Association for Mental Health (SAMH) was established in 1969 as the first community mental health agency in Singapore with the aim of providing quality step-down care and rehabilitative services to persons with mental health conditions. It is a non-profit, voluntary welfare organisation seeking to promote mental health in the community and improve the rehabilitation and reintegration of persons with mental illness.

Today, SAMH operates eight centres in Singapore, providing a comprehensive range of programmes and services:

**Centres**
- Activity Hub @ Pelangi Village
- Bukit Gombak Group Homes
- Club 3R (Toa Payoh)
- Club 3R (Jurong)
- Oasis Day Centre
- Insight Centre
- Creative Hub
- YouthReach

**Services**
- Counselling (Helpline & Appointments)
- Mobile Mental Health Outreach Team
- Community Mental Health Education
- Volunteer Programme
- Support Services
- Caregiver Support
- Peer Support
- Support for Eating Disorders Singapore
Vision

Mental Wellness For All

Values

Professionalism & Respect
Compassion & Acceptance
Hope & Empowerment
Engagement & Collaboration

Mission

To improve the lives of persons with mental illness and provide support for their families.

To promote acceptance and respect for persons with mental illness.

To improve the mental resilience of our community.
The promotion and maintenance of holistic wellness is the goal for many. Wellness is the philosophy of promoting health and preventing disease. (Malchiodi A. Cathy)

Creative Hub supports wellness by providing a variety of services for individuals to realize their own abilities to cope with the challenges of daily life, and function effectively in the family and community.

In a relaxed, mutually supportive, friendly environment we use various creative tools – movement, dance, music, art making, visualization and imagery -- to promote wellness.

Creativity is present in all of us as evident in our personal style and solutions we come up with for the challenges we face.
STEPHANIE KWOK

Lyric Composition Sessions.

“Although a few may have come to the course wondering what songwriting had to do with caregiving, it was heartening to see most eventually feeling they have achieved something, be it writing a full or half song or simply being more aware about how songs are written. But surely, and most importantly, is how the act of writing has perhaps helped a person gain self-confidence or allowed one to “let go” and put down into words some thoughts and feelings. I have enjoyed this journey with the caregivers.”

Aside from songwriting, Stephanie teaches drama, directs, produces, acts, writes songs and scripts for theatrical shows and is also a glass artist who has exhibited internationally.
SHARMINI WINSLOW

Dance and Movement Sessions.

“Creative Hub ran dance and movement sessions for caregivers this year. I was privileged to connect with many people who are dedicated to serving their loved ones and to being open and creative. The 4 sessions included self-care, assertiveness and stress management. Each week we experienced fun and spontaneity as we used drama as a form of therapy.

In December there was a 3-hour workshop also for caregivers. As the session progressed, the members of the group bonded and found a mutuality that both encouraged and inspired them to connect again.”
DEBORAH CHEN

**Art Making Sessions.**

Art helps people describe and express experiences and emotions that are too difficult to put into words. The sessions allowed participants to make artworks that brought meaning and memories to them. Through their reflections, they were able to draw out experiences to share amongst the group members. Given access to art-making, caregivers described the process as a transformative activity which enabled them to take greater control of their lives, resulting in feeling stronger, more confident, and more empowered in supporting their loved ones’ recoveries. Throughout this experience, I have had the privilege to journey with them and share in their stories. I personally hope that the caregivers will be able to follow up with support groups at Creative Hub, SAMH.
These sessions brought out memories, thoughts and reflections for most of the participants. It is indeed heartening to see caregivers coming together. Each individual is unique and brings with his or her personal experiences. The art experiential sessions were a time for closure to end the caregiver workshops. I believe that each person left on a positive note and with a better understanding of using art in a therapeutic context to learn that self-care is of utmost important. I am grateful to be a part of the project.
Caregiving is much more than just changing bedding and helping with bathing. A caregiver, for our intents and purposes, wears too many hats to list, and the list is ever-changing. It is one of the most deeply rewarding roles a person can assume but it can be emotionally, physically and mentally tiring to be giving continuously. Whilst caring for your loved one, it is important not to forget to love yourself as well. Caring for yourself is one of the most important — and one of the most often forgotten — things you can do as a caregiver. When your needs are taken care of, the person you care for will benefit too.

“Love Without Walls” provides a myriad of platforms such as movement, art, drama and music sessions to encourage caregivers to make time for themselves. In addition, the product of the different sessions is a form of individual self-expression and releasing of emotions that they may find hard to express.

Historically, the arts has been a platform for expressing emotions and story-telling. “Love Without Walls” aims to help caregivers realize the importance of self-care as they journey on this programme of expression through movement, art, drama and music.
THE EXPERIENCES

THE PROCESS
Feel the weight, hold on to each other...
Together.
Moments of laughter.
Spoken words.
“Meeting new friends, sharing in sessions, learning new skills, feeling a sense of relief.”
– K K Jek
Expressions.
“The remarkable thing is, we have a choice every day regarding the attitude we will embrace for that day.”
– Charles R. Swindoll, Author, Educator
Persona.
“I see the benefits of expressing myself through art as a form of therapy.” -Participant of “Love Without Walls”.

How old is your care recipient?
23 years old.

Could you share about your current caregiving journey?
We exchange text messages to share recent activities. Sometimes I will send inspirational articles. Occasionally we attend health talks or go for a show together.

Is it possible to give an account of one of the most painful incidents that happened for you and your care recipient?
It happened at midnight. He came crying to me and said that everything was fake and he felt betrayed. He always worked hard from a very young age. He told me that I have to learn how to look after myself as he felt he could not move on anymore. My heart sank. I hugged him tightly and both of us cried out hearts out. I begged him to give himself a chance and promised I would always stand by his side. At that moment, I was very frightened and lost. I knew that if he left, I would not be able to carry on living.

During this present journey as a caregiver, what are some of the positive and negative thoughts that have come to mind?
I must learn to accept and seek help. Trust the professionals who help us. Believe that he will recover. I do have some negative thoughts. I am worried that he
will have a relapse. Can we still pull through? Will he recover? Will he be able to take care of himself and lead a happy life? When he falls ill, I dare not leave him alone.

**Do you find it difficult to find time for yourself?**
Yes, it is quite hard to find time for myself.

**What is something that you miss doing?**
I love going on outings with others but I constantly worry about him being left alone.

**If you ever need support, what are the different types of support services would you turn to?**
Counselling, physiotherapy, support groups and studying inspirational articles.

**What form of support is the most essential to you as a caregiver?**
I think that counselling is the best form of support for me. During counselling sessions, I appreciate that my counsellor listens and offers some form of advice.

**Share three keywords of encouragement that keep you positive.**
Love, thanks, appreciation.

**What are some of the things you do to pamper yourself?**
I would attend free concerts and health talks. Visit various exhibitions. Join local tours and events that are organised by community clubs.
Are there times when you get frustrated?
Yes, when he was down with the illness and refused to heed any advice.

How do you resolve the frustration you feel as a caregiver?
I would force myself to stay calm and take some time to think about how else I can help him.

What did you learn during the sessions?
The lyric composition sessions enabled me to express my personal experiences and create a song. Dance and drama was fun and relaxing. I enjoyed myself very much.

If you were to meet another caregiver, what is one positive word you will share with them?
Love. It is what keeps me going.

Elaborate on some of the valuable experiences you will wish to share with other caregivers?
Self-care is of great importance. Sometimes caregivers carry with them a sense of guilt. However, I want to share that I would never have seen the importance of mental health if not for the workshops. I have learnt and come to understand the importance of mental wellness. It is always important to give encouragement and stay positive. Showing love is of utmost important.

-Chia
“Learn how to express our feelings and share our thoughts.”
– Angela
“There are only four kinds of people in the world: Those who have been caregivers, those who are currently caregivers, those will be caregivers and those who will need caregivers.”
– Rosalynn Carter
Pace.

Peace.
How old is your care recipient?
15 years old.

Could you share about your current caregiving journey?
It is very tough and challenging.

Is it possible to give an account of one of the most painful incidents that happened for you and your care recipient?
There was an incident where she was agitated because she was unable to leave the house. She pulled my hair. However, after the incident, she could not seem to recall what she had done to me.

During this present journey as a caregiver, what are some of the positive and negative thoughts that have come to mind?
From a positive point of view, I always believe that she will be well in the days to come. With the correct medication and patient guidance, I do believe she will recover. From a negative aspect, I thought about committing suicide with her. Fortunately, it never happened. The existence of her condition can sometimes be difficult for me to accept. There are times when I feel that it is unfair for me to be in this situation.
Do you find it difficult to find time for yourself?
Yes it is quite hard to find time for myself.

What is something that you miss doing?
I want to go back to work.

If you ever need support, what are the different types of support services would you turn to?
Talking to my friends and attending fellowship courses at church are forms of support for me. In addition, prayer is a form of support that my fellow sisters in Christ provide for me.

What form of support is the most essential to you as a caregiver?
Family support and understanding. However, these are the areas that I feel that I’m lacking in.

Share three keywords of encouragement that keep you positive.
Perseverance, love, patience.

What are some of the things you do to pamper yourself?
Having a good meal with a friend.

Are there times when you get frustrated?
Yes.

How do you resolve the frustration you feel as a caregiver?
I would walk away first and return when I have processed my thoughts.
**Which sessions did you attend?**

- **Lyrics composition**
  I attended the lyric composition sessions and I was able to express any frustration or anger through writing out the feelings.

- **Drama and movement**
  In the sessions, I had the chance to do a role-play. The role-playing sessions taught us how to reflect on our actions and thoughts. In addition, the sessions also provided technical strategies on handling our emotions. There was emphasis placed on the importance of self-care. It ended with an impact for me. The last session was a dialogue session where the participants gave comments and suggestions on the thoughts that we have about each other. There was something new to me and it was a good and rewarding experience.

- **Art – Mask-making**
  I did a mask based on my theme. I enjoyed the art-making process.

**What were some of the struggles you had while attending the sessions?**

During the sessions, I was worried that my care recipient would be unstable. Thankfully, Creative Hub provided an extra activity for my care recipient.
What is your take away from the sessions you attended?
I learnt that responsibility should be shared.

What are some of the changes in attitude or perspective you noticed when you were at home?
I realized the importance of taking time off for myself. I started taking time off to meet my friends, attending church fellowship and I will leave my care recipient under the care of my husband.

Was it difficult to apply some of the methods learnt during the sessions at home?
It is not easy to tell others the truth about my situation. I find it hard to trust others.

If you were to meet another caregiver, what are some thoughts you will like to share with them?
Caregiving takes a lot of love and patience. Stay positive and take good care of yourself. Find a supportive community that you can share with and trust.

Elaborate on some of the valuable experiences you will wish to share with other caregivers?
These challenges have helped me to become a stronger person. They have shown me the importance of staying calm. When a caregiver is frustrated, the care recipient is able to sense that frustration. Be firm and do not apply pressure on the care recipient. When in doubt, seek advice from a counsellor. Last but not least, I always pray for my care recipient.

*Participant of Love without walls.*
“To be appreciative and thankful and to live life to the fullness. To help and serve the community whenever you can.”
– Irene Lim
“The greatest act of faith some days is to simply get up and face another day.”
– Amy Gatliff
A touch that relates.
“I feel very happy as I can make more friends and learn from shared experiences. I always believe that there is no age barrier to learning. To me, age is only a number, it’s all in your mind. So it’s always good to be positive.”
-Irene Lim
“Having courage does not mean that we are unafraid. Having courage and showing courage means we face our fears. We are able to say, ‘I have fallen, but I will get up’.”
– Maya Angelou
The stage is yours.
“It reminds me of the times I shared with my children and nephew when we visited my mother during the school holidays. This also brings back memories of my mother who used to be active. However, at age 88, she is now bedridden.”
– Chia
How old is your care recipient?
My care recipient is 59 years old.

Could you share about your current caregiving journey?
My current caregiving journey has not been an easy one as being the main caregiver for my husband, Nicholas who was diagnosed with throat cancer in 2010. When I came to know that Nicholas has throat cancer, I was feeling very sad and deep down inside me I was telling myself that I have to be prepared for the worst as Nicholas will not be able to talk again for the rest of his life. So I will have to be well prepared that I will only be able to communicate with him through writing and SMS. Thanks to the new technology.

Is it possible to give an account of one of the most painful incidents that happened for you and your care recipient?
Nicholas actually went through more than 45 sessions of radiotherapy in the beginning and was well but when he went back for his review after one year, his doctor found that there was a cancerous tumour below his voice-box. His doctor told us that radiotherapy and chemo will not worked for him. When his doctor broke the bad news to us, we were actually feeling very sad about it. We can’t do much but to accept the fact and face reality. His doctor told us that surgery to remove his voice-box is the best treatment for him. It was so unfortunate that Nicholas actually went through 5 surgeries within a year. His first surgery to remove his voice-box was done on 12 Aug 2010. It was a very long operation from morning to evening.

Nicholas actually undergone 5 operations within a year and to make things worst he was down with shingles so he had to be isolated from the normal ward. He actually stayed in the hospital for more than 8 over months because his wound does not heal or close up properly so his doctor has to do a minor operation for skin grafting from his thigh and chest to close up his wound.
One Saturday afternoon when I visited Nicholas in the hospital after his 4th operation, he actually told me that he did not want to suffer anymore and he wanted to give up. Upon hearing that, I knew that he was in great pain because he was very drowsy and did not wake up and eat his meal for about 3 to 4 days and have lost quite a lot of weight. I have never seen Nicholas losing so much weight in all his life. Upon hearing that I told him that I don’t believe God will not heal him. He will heal him but at His own time and only He knows when is the perfect time. I also told him to keep drawing strength from God as he is not alone, my Pastors and church members are praying for him and the whole church are behind him. Upon hearing that, day by day Nicholas managed to overcome the very tough times and his condition got better and better each day.

**During this present journey as a caregiver, what are some of the positive and negative thoughts that have come to mind?**

Some of the positive thoughts that come to my mind are no matter how challenging and tough the journey is, I still have to try and not give up because I always believe cancer is not a death sentence and with the very advance medical treatment, Nicholas will definitely be able to get well again. I cannot afford to breakdown because if I breakdown or give up then Nicholas will also give up as I am his pillar of strength.

I do not have any negative thoughts as I am a very positive minded person. When I first knew that Nicholas was diagnosed with throat cancer, the first thing I told him is that he has to be very positive because if he is negative nobody can help him.

**Do you find it difficult to find time for yourself?**

Yes, at times I find it hard to find time for myself as I have to work the whole day and visit Nicholas at the hospital. I am a very active person but because of Nicholas I have to cut down some of my community activities.

**What is something that you miss doing?**

The something that I miss doing is my aerobic exercise in the gym and catching up with all my siblings and networking with all my good friends.

**If you ever need support, what are the different types of support services would you turn to?**

Praying to God and reading God’s word daily, attending small cell group in church, sharing my problems with my siblings and reading very inspirational books like ‘Life without Limits’ by Nick Vujicic.
**What form of support is the most essential to you as a caregiver?**
To me, I think moral and financial support from my siblings that show love, care, concern, understanding and patient is the most essential support that anybody can ask for.

**Share three keywords of encouragement that keep you positive.**
The three keywords of encouragement that keep me positive are love, appreciation and perseverance.

**What are some of the things you do to pamper yourself?**
Attending free health workshop, catching up and having a good meal with wonderful friends and going for facial and massage.

**Are there times when you get frustrated?**
Yes, especially when I try to encourage him to change his lifestyle, eat healthily and do his exercise and he didn't take my advice.

**How do you resolve the frustration you feel as a caregiver?**
I will always try to stay calm and patient and do some reflection on how I will be able to help Nicholas to get well faster.

**Which sessions did you attend?**
The lyric composition session has enabled me to express my sadness through writing out my feelings and giving me joy through listening to all the wonderful music.

As for the drama and movement session where I was given a chance to do a role-play. The role-play session has taught me to reflect on my actions and thoughts. It was a fun and relaxing session and I really enjoyed myself very much. I am very sure that the rest of the participants also enjoyed them-selves very much as seen from their laughter and expressions on their faces.

The art experiential sessions was also very relaxing and fun as we got a chance to be creative and learn to make our own photo frames.

**What were some of your struggles you had while attending the sessions?**
I do not have any struggles while attending the sessions as the sessions were fun and relaxing so I always looked forward to come for the sessions.
What is your take away from the sessions you attended?
The take away from the sessions that I have attended is to be active, healthy, happy and appreciative with your life and to live life to the fullest and to help the needy in our community.

What are some of the changes in attitude or perspective you noticed when you were at home?
I realised that I need to make time to go for my exercise to distess myself, for I know that I cannot breakdown because if I break down, Nicholas will also break down as I am his pillar of strength.

Was it difficult to apply some of the methods learnt during the sessions at home?
It has not been easy applying the methods learnt from the sessions as not many people will be able to understand your situation unless they have experienced it before and it is not easy to confide in someone whom you can trust.

If you were to meet another caregiver, what is one positive word you will share with them?
It’s never easy to be a main caregiver as it takes a lot of love, patience and strength to move on. Always stay positive, be strong and remember that you are never alone. We have a caring and supportive community that you can trust to share your burden and give you support through prayers and encouragement.

Elaborate on some of the valuable experiences you will wish to share with other caregivers?
Going through these very difficult times the last 3 years have definitely made me a stronger person.

I have also learnt that I must take care of myself well before I can take care of others. Last but not least, I would like to share with other caregivers is that whatever situation you are in, always stay positive and calm, have faith, believe and trust that God will heal.

-Irene Lim, Participant of Love without walls.
The key to caring for ourselves lies in the acceptance of the fact that our loved ones have medical conditions. Communication skills aid in the understanding of our loved ones and allow us to show them love and support.

Self-care is essential for all caregivers in order to maintain quality of life and to ensure that we are able to care for our loved ones too. If you are in need of help, take the first step to contact agencies.

Together with a good support system, we and our loved ones can look forward to journeying together towards recovery and wellness.

Remember to do things that you enjoy, that make you feel good, that make you happy, that give you hope.
Taking care of your health and well-being does not make you selfish.

Taking care of your health and well-being will make you a stronger, happier person so that you can live each day with purpose and joy.
The Family Link Programme is a 9-session workshop run by Singapore Association for Mental Health (SAMH) for caregivers of persons with any one of the 3 kinds of mental illnesses: Depression, Bipolar Disorder (Manic-Depressive Disorder) or Schizophrenia. SAMH runs Family Link Programme classes in both English and Mandarin on a quarterly basis. The first Malay class commenced in August 2012.

Origin of Family Link Program

The Family Link Programme was developed in Hong Kong in 2000 by Dr Marcus Chiu, a Social Work Professor and Professor Sing Lee, a psychiatrist, after recognizing the need to educate and support family members of persons with mental illness to empower them to care for their loved ones. Topics for the Family Link Program
1. Introduction to Family Link Program/Understanding Mental Illness (part 1)

2. Understanding Mental Illness (part 2) – Schizophrenia, Depression & Bipolar Disorder

3. Practical Drug Guide & Management

4. Effective Communication with Persons with Mental Illness

5. Handling Crisis & Suicide Prevention

6. Treating Yourself Good

7. Recovery/Overview of Mental Health Services

8. Dealing with Stigma & Discrimination

9. Moving Forward

Registration forms may be downloaded from SAMH’s website www.samhealth.org.sg

For further enquiries, please call SAMH Helpline 1800 – 283 7019.
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Services Provided:
- Counselling & Support Group
- Psycho-educational Group

Please log on to our website, www.samhealth.org.sg, for more information. For general enquires on general mental health matters, please call our toll-free Helpline: 1800-283 7019 (9am-1pm, 2pm-6pm, weekdays, except public holidays) or email counselling@samhealth.org.sg
Singapore Anglican Community Services

Address : Blk 10 Simei Street 3, Singapore 529897
Tel : 6586 1064
Email : admin@sacs.org.sg
Website : www.sacs.org.sg

AWWA Centre for Caregivers (AWWA CFC)

Address : No. 11 Lorong Napiri, Singapore 547532
Tel : 6511 5318
Fax : 6511 5319
Website : www.awwa.org.sg
Email : awwacfc@awwa.org.sg

Alzheimer’s Disease Association (ADA) Caregiver Support Centre

Address : New Horizon Centre (Jurong Point)
1 Jurong West Central 2, #04-04
Jurong Point Shopping Centre
Singapore 648886
Tel : 6377 0700
Email : registration@alz.org.sg
Website : www.alz.org.sg
Caregiving Welfare Association (CWA)

Address: 3 Ghim Moh Road, #01-294, Singapore 270003
Tel: 6466 7957
Website: www.cwa.org.sg
Email: contact@cwa.org.sg

St Andrew’s Community Hospital

Address: 8 Simei Street 3, Singapore 529895
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To love and to hold.